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To Whom it may concern,

My name is Yujuan Zhang. I am a pediatric rheumatologist at Floating Hospital for Children at Tufts Medical Center, Boston, MA. I am writing to support the bill HB 2721.

As a provider treating Pediatric Autoimmune Neuropsychiatric Disorders (PANS), I have encountered many issues in adequately caring for our patients. There is an obvious gaping hole when it comes to treating children with PANDAS/PANS. Now is the time to change the clinical outcomes for this pediatric population by ensuring that a full range of treatment options are widely available based on the clinical judgement of the healthcare providers who serve them.

Based on peer-reviewed and published clinical evidence, there are three prongs of treatment modalities that are regularly employed by physicians when treating cases of PANDAS/PANS: treating the SOURCE of infection; resolving the SYMPTOMS; and modulating the immune SYSTEM response to infections. For ease in understanding, the National Institute of Mental Health has come up with this mnemonic: Treat the 1. Source 2. Symptoms and 3. System. At present, doctors who care for children with moderate to severe PANDAS/PANS are unable to provide appropriate treatment because insurers are disregarding physicians' treatment plans when immunomodulatory system treatments are required.

In formulating and adopting medical policies with respect to covered services, it is understood that insurers shall rely on

- **A.)** "credible scientific evidence published in peer-reviewed medical literature generally recognized by the relevant medical community, and shall continue to make such policies readily available to its Plan Members and Participating Physicians via its Public Website or by other electronic means. In the adoption of such policies, each Blue Plan
- **B.)** shall take into account national Physician Specialty Society recommendations and the views of prudent Physicians practicing in relevant clinical areas and
- C.) any other clinically relevant factors.

Promptly after adoption, a copy of each new policy or guideline shall be filed with its Physicians' Advisory Committee." In addition, within Blue Cross Blue Shield plans, "if a Physician Specialty Society recommends as an appropriate standard of care a new technology or treatment, or a new use for an established technology or treatment, the Blue

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Plan shall evaluate such recommendation and <u>issue a coverage statement not later than</u> 120 days after the Blue Plan learns of such Physician Specialty Society recommendation." (Adapted from Love Settlement

http://www.naic.org/documents/legal love settlement.pdf)

A.) Studies that prove antibiotics (ABX), IVIG, and Plasmapheresis (PEX) are effective for reduction in severity of PANDAS/PANS symptoms date back to The Lancet in 1999, and are followed up more recently in peer reviewed journals and policies throughout the world. There are currently three different additional papers supporting the use of a full range of treatment have currently been submitted to Journal of the American Academy of Child and Adolescent Psychiatry for publication as well. They are to be published in April/May of 2017.

ABX https://www.ncbi.nlm.nih.gov/pubmed/26866234 Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS). Orefici G, Cardona F, Cox CJ, Cunningham MW. Ferretti JJ, Stevens DL, Fischetti VA, editors. https://streptococcus.pyogenes: Basic Biology to Clinical Manifestations [Internet]. Oklahoma City (OK): University of Oklahoma Health Sciences Center; 2016 Feb 10. "PANDAS is clearly a subtype of PANS (Murphy, et al., 2015b; Murphy, Parker-Athill, Lewin, Storch, & Mutch, 2015a; Chang, et al., 2015) and not all PANS cases have an underlying streptococcal infection—but all PANDAS cases are associated with streptococcal infections, at least temporally. When these diseases appear, treatment with antibiotics can be successful, and a treatment trial of cerdinir by Murphy and colleagues indicated that therapy with cerdinir, a β lactam antibiotic, provided notable improvements in tic symptoms rated by the Yale Global Tic Severity Scale (YGTSS) and OCD symptoms rated by the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS). However, the differences within the groups as a whole were not significant. β-lactam antibiotics have been proposed to be neuroprotective above and beyond their antibiotic efficacy (Murphy, Parker-Athill, Lewin, Storch, & Mutch, 2015a)."

ABX http://jamanetwork.com/journals/jamaotolaryngology/fullarticle/2089440 The role of tonsillectomy in the treatment of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS). Demesh D, Virbalas JM, Bent JP. JAMA Otolaryngol Head Neck Surg. 2015 Mar;141(3):272-5. doi: 10.1001/jamaoto.2014.3407. "Ten patients met strict diagnostic criteria for PANDAS. Comparisons were made between parental reports of symptom severity at diagnosis, after antibiotic treatment (in 10 patients), and after tonsillectomy (in 9). From a baseline severity score of 10, antibiotics alone improved symptoms to a median (interquartile range [IQR]) score of 8 (6.5-10.0) (P = .03). Nine children who subsequently underwent tonsillectomy reported symptom improvement in comparison with treatment with antibiotics alone, including those with no response to antibiotics."

ABX https://www.ncbi.nlm.nih.gov/pubmed/24187894 Suspect PANDAS in children with acute neuropsychiatric symptoms. Infection behind the disease - long-term antibiotic therapy should be considered. Bejerot S, Bruno K, Gerland G, Lindquist L, Nordin V, Pelling H, Humble MB, Lakartidningen. 2013 Oct 9-15;110(41):1803-6. Review. Swedish. "long-term antibiotic therapy should be considered."

ABX https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3440267/ Pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections. Tan J, Smith CH, Goldman RD. Can Fam Physician. 2012 Sep;58(9):957-9. "Positive results have been found using antibiotic prophylaxis and immunomodulatory therapy in children with PANDAS."

ABX https://www.ncbi.nlm.nih.gov/pubmed/22234571 Successful treatment with benzathine penicillin of two patients suspected of suffering from PANDAS. Redondo-Granado MJ, García-Saseta P, Vizcaíno-López I, Palencia-Luaces R. Redondo-Granado MJ, García-Saseta P, Vizcaíno-López I, Palencia-Luaces R. Redondo-Granado MJ, García-Saseta P, Vizcaíno-López I, Palencia-Luaces R. Redondo-Granado MJ, García-Saseta P, Vizcaíno-López I, Palencia-Luaces R. Redondo-Granado MJ, García-Saseta P, Vizcaíno-López I, Palencia-Luaces R. Redondo-Granado MJ, García-Saseta P, Vizcaíno-López I, Palencia-Luaces R. Redondo-Granado MJ, García-Saseta P, Vizcaíno-López I, Palencia-Luaces R. Redondo-Granado MJ, García-Saseta P, Vizcaíno-López I, Palencia-Luaces R. Redondo-Granado MJ, García-Saseta P, Vizcaíno-López I, Palencia-Luaces R. Redondo-Granado MJ, García-Saseta P, Vizcaíno-López I, Palencia-Lopez I, Palencia-L

ABX https://www.ncbi.nlm.nih.gov/pubmed/19226494 Tic disappearance after penicillin treatment in a patient with PANDAS. Aguilera-Albesa S, Sánchez-Carpintero R, Villoslada-Díaz P. Rev Neurol. 2009 Feb 16-28;48(4):221-3. Spanish

ABX https://www.ncbi.nlm.nih.gov/pubmed/18079308 Mycoplasma pneumoniae infection and obsessive-compulsive disease: a case report. Ercan TE, Ercan G, Severge B, Arpaozu M, Karasu G. J Child Neurol. 2008 Mar;23(3):338-40. "After treatment with oral clarithromycin, all his obsessive-compulsive disease symptoms disappeared."



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ABX https://www.ncbi.nlm.nih.gov/pubmed/15820236 Antibiotic prophylaxis with azithromycin or penicillin for childhood-onset neuropsychiatric disorders. Snider LA, Lougee L, Slattery M, Grant P, Swedo SE. Biol Psychiatry. 2005 Apr 1;57(7):788-92. "Penicillin and azithromycin prophylaxis were found to be effective in decreasing streptococcal infections and neuropsychiatric symptom exacerbations among children in the PANDAS subgroup."

ABX www.ncbi.nlm.nih.gov/pubmed/10933123 Infection-triggered anorexia nervosa in children: clinical description of four cases. Sokol MS. J Child Adolesc Psychopharmacol. 2000 Summer; 10(2):133-45. "The patients responded to conventional treatment plus antibiotics with weight restoration and decreased eating disorder and obsessive-compulsive symptoms."

IVIG and PEX <a href="http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(98)12297-3/fulltext?version=printerFriendly Therapeutic Plasma Exchange and Intravenous Immunoglobulin for Obsessive-Compulsive Disorder and Tic Disorders in Childhood, Perlmutter, Susan J et al. The Lancet/1999, Volume 354, Issue 9185, 1153 – 1158 "Plasma exchange and IVIG were both effective in lessening of symptom severity for children with infection-triggered OCD and tic disorders."

IVIG and PEX https://www.ncbi.nlm.nih.gov/pubmed/15871831 Fernández Ibieta MAn Pediatr (Barc). 2005 May;62(5):475-8. Neuropsychiatric Disorders Associated with Streptococci: A Case Report "Current recommendations include penicillin treatment of each exacerbation with positive throat culture, and more aggressive therapies (intravenous immunoglobulin or plasmapheresis) when symptoms are severe."

PEX http://www.ncbi.nlm.nih.gov/pubmed/16239863 PANDAS with Catatonia: A Case Report. Therapeutic response to lorazepam and plasmapheresis. J Am Acad Child Adolesc Psychiatry. 2005 Nov;44(11):1145-50. "Plasmapheresis resulted in significant and rapid clinical improvement of obsessive-compulsive disorder symptoms and a simultaneous decrease in basal ganglia swelling, consistent with an immune-mediated pathophysiological process involving group A beta-hemolytic streptococci."

IVIG http://www.bloodmed.com/contentimage/guidelines/2854.pdf Evidence-Based Guidelines on the Use of Intravenous Immune Globulin for Hematologic and Neurologic Conditions Paula Robinson, David Anderson, Melissa Brouwers, Thomas E. Feasby, and Heather Hume, on behalf of the IVIG Hematology and Neurology Expert Panels. Iransfus Med Rev. 2007 Apr;21(2 Suppl 1):S3-8. "Use in Canada Pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS). In the opinion of the expert panel, it is reasonable to consider IVIG among the options for treatment. IVIG is recommended as an option for treatment of patients with PANDAS. (Review of Lancet, 1999, listed above.) Based on consensus by the expert panel, diagnosis of PANDAS requires expert consultation."

IVIG https://www.ncbi.nlm.nih.gov/pubmed/17397768 Guidelines on the use of intravenous immune globulin for neurologic conditions. Feasby T, Banwell B, Benstead T, Bril V, Brouwers M, Freedman M, Hahn A, Hume H, Freedman J, Pi D, Wadsworth L. Transfus Med Rev. 2007 Apr;21(2 Suppl 1):S57-107. "A panel of 6 clinical experts, one expert in practice guideline development and 4 representatives from the... Canadian National Advisory Committee on Blood and Blood Products...met to review the evidence and reach consensus on the recommendations for the use of IVIG for... 22 neurological conditions. Recommendations for use of IVIG were made for 14 conditions, including acute disseminated encephalomyelitis, chronic inflammatory demyelinating polyneuropathy, dermatomyositis, diabetic neuropathy, Guillain-Barré syndrome, Lambert-Eaton myasthenic syndrome, multifocal motor neuropathy, multiple sclerosis, myasthenia gravis, opsoclonus-myoclonus, pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections, polymyositis, Rasmussen's encephalitis, and stiff person syndrome. Intravenous immune globulin is recommended as an option for treatment of patients with PANDAS. Based on consensus by the expert panel, diagnosis of PANDAS requires expert consultation. Based on consensus by the expert panel, a total dose of 2 g/kg given over 2 days is recommended as a reasonable option."

IVIG https://www.blood.gov.au/system/files/documents/NBA IVIQCriteria Second Edition Internals-www.blood.gov.au/system/files/documents/NBA IVIQCriteria Second Edition InternalsWEB updated ref.pdf Criteria for the Clinical Use of Intravenous Immunoglobulin in Australia Second Edition July 2012 "Paediatric autoimmune neuropsychiatric disorder associated with streptococcal infection (PANDAS) Level of Evidence 2a PANDAS was first described in the early 1990s. PANDAS is characterised by rapid-onset tics associated with obsessive compulsive disorder (OCD) in the context of recovery from streptococcal infection. Molecular mimicry between streptococcal antigens and the central nervous system is thought to underlie the cause. Symptomatic therapy is used with variable response. A single randomised placebo-controlled trial using IVIg for PANDAS showed very prolonged and significant improvement in obsessive-compulsive symptoms, anxiety, depression, emotional lability and overall function compared with placebo. Improvements in symptoms were still evident at one-year follow-up. Refer to the current product information sheet for further information. The aim should be to use the lowest dose possible that achieves the appropriate clinical outcome for each patient.

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IVIG http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4213893/ Intravenous Immunoglobulin in Pediatrics: A Review Med J Armed Forces India. 2014 Jul; 70(3): 277–280. "There are many disorders for which IVIG is used as a treatment in children. Some of the common indications can be grouped as: a) Neurology – Guillain Barre syndrome, Chronic inflammatory demyelinating polyradiculopathy (CIDP), Dermatomyositis and inflammatory myopathies, Myasthenia gravis, rare childhood epilepsy (Lennox gastaut seizure, Landau Kleffner seizure), Opsoclonus myoclonus ataxia, PANDAS (Paediatric autoimmune neuropsychiatric disorders associated with streptococcal infection) – OCD, anxiety, depression, emotional lability."

IVIG and PEX http://www.tandfonline.com/doi/pdf/10.1080/21645515.2015.1061161 Giovanna Vitaliti, Omidreza Tabatabaie, Nassim Matin, Caterina Ledda, Piero Pavone, Riccardo Lubrano, Agostino Serra, Paola Di Mauro, Salvatore Cocuzza & Raffaele Falsaperla (2015) *The usefulness of immunotherapy in pediatric neurodegenerative disorders: A systematic review of literature data*, Human Vaccines & Immunotherapeutics, 11:12, 2749-2763 "In the studies we analyzed, IVIG was (sic) found to be efficient in the treatment of post-streptococcal neurodegenerative disorders, even if in PANDAS, plasma-exchange (PE) showed a higher efficiency."

IVIG http://online.liebertpub.com/doi/full/10.1089/cap.2014.0067 The Use of Intravenous Immunoglobulin in the Treatment of Twelve Youths with Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

Kovacevic Miro, Grant Paul, and Swedo Susan E. Journal of Child and Adolescent Psychopharmacology. February 2015, 25(1): 65-69. Please note that under the section entitled, Clinical Significance, "For optimum symptom relief, it is necessary to utilize a combination of immunomodulatory therapy, antibiotic prophylaxis, and targeted symptom treatments, as described at the PANDAS Physicians Network (PPN) (www.pandasppn.org). The website presents a systematic graduated approach to treatment of PANDAS/PANS based on the best practice standards of expert clinicians from across the United States. In addition to providing suggestions for recognition and diagnosis of PANDAS/PANS, it also offers guidance in the management of patients with varying levels of severity." For reference, the PANDAS Physicians Network website: https://www.pandasppn.org/therapeutic-options-for-pandas-and-pans/

PEX http://online.liebertpub.com/doi/abs/10.1089/cap.2014.0080 Therapeutic Plasma Apheresis as a Treatment for 35 Severely III Children and Adolescents with Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections Latimer M. Elizabeth, L'Etoile Nathan, Seidlitz Jakob, and Swedo Susan E. Journal of Child and Adolescent Psychopharmacology. February 2015, 25(1): 70-75. "Therapeutic plasma apheresis is an invasive medical intervention that should be reserved for treatment of children and adolescents who are severely affected by PANDAS. In such patients, it appears to be a safe, well-tolerated, and beneficial treatment option."

IVIG http://www.ghrnet.org/index.php/ijnr/article/view/1633/1896 Infection-Induced Autoimmune Encephalopathy: Treatment with Intravenous Immune Globulin Therapy. A Report of Six Patients. Bouboulis Dennis. Mast Phyllis. International Journal of Neurology Research, Vol 2, No 1 (2016) "IVIg is a safe and beneficial therapy in IIAE, PANDAS and ASD impacting favorably on underlying humoral immune deficiency and infectious-induced CNS autoimmunity in this small and highly selected cohort."

IVIG http://www.jaacap.com/article/S0890-8567(16)31158-3/pdf Randomized, Controlled Trial of Intravenous Immunoglobulin for Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infection.

October 2016. Volume 55, Issue 10, Pages 860–867.e2. As reported by the PANDAS Physicians Network, "a new paper submitted to the Journal of the American Academy of Child & Adolescent Psychiatry describes the outcome of the NIMH double-blind placebo controlled study of IVIG for treatment of symptoms in children who meet the criteria of PANDAS. While the study has many interesting findings, the most significant is that children who had prophylactic antibiotics followed by an open-label IVIG had a >60% mean reduction in CYBOCS score. These symptom improvements were sustained through follow up at 6 months."

IVIG https://www.ncbi.nlm.nih.gov/pubmed/27900773 Systemic Review of Immunoglobulin Use in Paediatric Neurological and Neurodevelopmental Disorders Dev Med Child Neurol. 2017 Feb;59(2):136-144. "We conclude that it is likely that IVIG improves recovery in selected patients with paediatric autoimmune neuropsychiatric disorder associated with streptococcal infection (level 2). We recommend that IVIG should be considered in selected patients with a diagnosis of paediatric autoimmune neuropsychiatric disorder associated with streptococcal infection (grade B)." Oxford Centre for Evidence-based Medicine — Levels of Evidence (March 2009)

IVIG http://dx.doi.org/10.1016/j.jaci.2016.09.023 Update on the use of immunoglobulin in human disease: A review of evidence The Journal of Allergy and Clinical Immunology. March 2017 Volume 139, Issue 3, Supplement, Pages S1-S46 "The immune-based therapies should be used only in cases in which it is clear that the neuropsychiatric symptoms are related to an autoimmune response, as supported by laboratory evidence and in conjunction with neuropsychiatric professionals."

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Subsequently, in 2013, PEX as a frontline treatment was accepted as standard of care for PANDAS/PANS, and is now covered by all insurance groups.

http://italkid.org/Guidelines%20on%20the%20Use%20of%20Therapeutic%20Apheresis%20 in.pdf.

Based on scientific information, and the precedent set by the PEX adoption, IVIG has been accepted as standard of care for treating PANDAS/PANS and should be adopted by insurers expediently. The current gap in health insurance coverage is causing disruption in physicians' medical practices, as well as an undue financial burden on families whose children have PANDAS/PANS.

B.) Specific recommendations supporting a full range of treatment options for children with PANDAS/PANS, including but not limited to IVIG, come from these national **Physician Specialty Societies**:

The PANDAS Physicians Network
The PANDAS/PANS Collaborative Consortium

As well as from these "prudent Physicians practicing in relevant clinical areas:"

Harvard (MGH) - Kyle Williams & Dan Geller (Child Psych), Mark Pasternack (Peds ID)

Yale - James Leckman, Robert King (both Child Psych)

Columbia – Dritan Agalliu (basic science of blood-brain barrier), Mady Hornig

(Neuroimmunology)

Nemours/Delaware Children's Hospital – Jo Elia (Child Psych), Harry Chugani (PET neuroimaging)

NIMH - Susan Swedo (Pediatrics), Rebecca Hommer & Paul Grant (Child Psych)

Georgetown - Beth Latimer (Peds Neuro), Earl Harley (ENT)

UNC - Jim Crowley (Genetics)

Univ South Florida - Tanya Murphy (Child Psych), Jolan Walter (Immunology)

Loyola Univ (Hinsdale IL) - Miro Kovacevic (Peds)

Univ Minnesota - Pat Cleary (basic science, microbiology of Group A strep)

Baylor University - Eyal Muscal (Peds Rheumatology)

Univ Oklahoma – Madeleine Cunningham (GAS microbiology; immune response to infection)

Univ Arizona - Sydney Rice (Dev/Behav Peds) & Michael Daines (Peds Immuno)

Stanford – Jenny Frankovich (Peds Rheumatology), Margo Thienemann & Kiki Chang (Child Psych)

Ad hoc members: Moleculera Labs - Craig Shimasaki (antibody testing)

PANDAS Physicians Network - David Brick (Peds Cardiology)

C.) "Other clinically relevant factors" include:

*Sites of Current/Proposed PANDAS/PANS Centers of Clinical Excellence as determined at the National Institute of Health Organizational Meeting April 18-19, 2016

- 1.) Harvard/Mass General Hospital-Kyle Williams (Child Psych) & Mark Pasternack (Peds ID)
- 2.) Columbia University-NYC-Dritan Agalliu; Robert Fryer, Wendy Vargas (Peds Neuro)
- 3.) DuPont University- New Jersey-Harry Chugani (Peds Neuro) and Jo Elia (Child Psych)

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- 4.) Georgetown University-Washington DC-Beth Latimer (Peds Neuro); Earl Harley (Peds ENT)
- 5.) University of South Florida-Tanya Murphy (Child Psych/Pediatrics); JoLan Walter (Peds Immuno)
- 6.) Nationwide Children's-Columbus, OH-Dan Coury
- 7.) University of Missouri-Mike Cooperstock (Peds ID) and Thompson Center (Behavioral Peds)
- 8.) University of Minnesota-Minneapolis, MN-Gail Carlson (Child Psych)
- 9.) Baylor University-Houston, TX- Eyal Muscal (Peds Rheum and Neuro)
- 10.) University of Arizona-Michael Daines (Peds Immuno); Sidney Rice (Dev/Behav Peds)
- 11.) Standford University-Jenny Frankovich (Peds Rheum); Margo Theinemann and Kiki Chang (Child Psych)
- 12.) UCSD-San Diego, CA-Jay Giedd (Child Psych)
- 13.) University of Saskatchewan-Saskatoon, CAN-Alan Rosenberg (Peds Rheum) and others across province.

Throughout 2016 and early 2017 alone, numerous educational, legislative, and awareness activities have taken place throughout the county that show how clinically relevant and much needed the spread of information is in regards to PANDAS/PANS.

- *The Illinois PANDAS/PANS Advisory Council, working closely with the Illinois Department of Public Health, has formulated a plan to bring about widespread awareness of diagnostics and treatments throughout the state based on the adopted standard of care from the NIMH and PANDAS Physicians Network's Diagnostic and Treatment Guidelines. "Relevant" Illinois doctors participating on the Advisory Council include: Dr Anette Mnabhi, DO (family practice/osteopathy); Dr Natalie Drummond-Lambajian, MD (pediatrics); Dr Greg Sharon, MD (immunology); Dr Anju Usman, MD (family practice/autism specialist), and Dr Pamela Campbell, MD (psychiatrist). The council also includes members such as social workers, psychologists, school professionals, and parents. Dr Sue Swedo, the medical research member of the committee, has presented the most current diagnostics and treatment information to the group on two occasions. This past August, representatives from the State's Attorney's office and the IL Department of Insurance participated in the discussion of standard treatment options.
- * In March 2016, the American Academy of Pediatrics passed a resolution to conduct a scientific review of the literature supporting a causative role for Group A streptococcal infections in PANDAS. While awaiting their confirmation of the relationship, it is recommended that physicians follow the diagnostic guidelines for PANDAS/PANS, as published in the Journal of Child and Adolescent Psychopharmacology paper, Clinical Evaluation of Youth with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS): Recommendations from the 2013 PANS Consensus Conference https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4340805/
- *The Arizona Ad Hoc Advisory Council on Pediatric Autoimmune Neuropsychiatric Disorders recently released Clinical Guidelines and Recommendations on the state's Department of Health Services website http://www.azdhs.gov/audiences/clinicians/#guidelines-



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<u>recommendations-pans-pandas</u>. In February 2016, AZ legislature appropriated \$1,000,000 to the Department of Health Services for research, diagnosis, and treatment of Pediatric Autoimmune Neuropsychiatric Disorders.

- *The Massachusetts Child Psychiatry Access Project focused their April 2016 newsletter on PANDAS https://www.mcpap.com/pdf/MCPAP%20April%202016%20Newsletter.pdf
- * Massachusetts, Connecticut and Illinois are working on legislation that will provide for the full range of treatments to be covered by insurers. Twenty seven other states are also mobilizing to do the same.
- *The International OCD Foundation has supported the PANDAS/PANS diagnosis for many years.
- *The Departments of Health in both Arizona and Virginia now include PANDAS/PANS information as a part of their websites.
- *The Illinois Department of Public Health website includes PANDAS/PANS information including the 2016 PANDAS/PANS Advisory Council Report which details the Standards of Care.
- *Grand Rounds at University of Arizona Feb 11, 2016 https://streaming.biocom.arizona.edu/event/?id=26410&play=1&format=sd
- *Grand Rounds at National Institute of Health April 20, 2016 https://videocast.nih.gov/summary.asp?Live=18935&bhcp=1Now
- *PANDAS/PANS Track at the International OCD Foundation Annual Conference, Chicago, IL July 29–31, 2016
- *Grand Rounds at University of Chicago Comer Children's Hospital August 4, 2016
- *Grand Rounds at Charlotte Pediatric Society, North Carolina October 4, 2016
- *Grand Rounds at Levine Children's Hospital, Charlotte, North Carolina October 5, 2016
- *The third annual PANDAS/PANS Awareness Day took place on October 9, 2016 in many states throughout the country.
- *International conference: PANDAS/PANS 2016: An Update on Current Management and New Treatment Strategies at Georgetown University, October 15-16, 2016. **CMEs were provided to physicians.**
- *PANDAS/PANS Symposium for Physicians and Families, Omaha, NE November 12, 2016



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*Screenings of the PANDAS/PANS documentary My Kid Is Not Crazy: A Search for Hope in the Face of Misdiagnosis have taken or will take place throughout the Fall 2017/Winter-Spring 2017 in Washington DC; Chicago; San Francisco; Gainesville,FL, Richmond, VA; Little Rock, AR; Boston, MA; Fairfield, CT

* A Standards of Care Summit of all the IL State Professional Societies and interested parties was convened on February 8, 2017 to discuss appropriate care strategies aligned with the the guidelines from the NIMH, the PANDAS Physicians Network and the IL PANDAS/PANS Advisory Council. BCBS Medical Director was in attendance.

*Link to Treatment Guidelines from PANDAS Physicians Network https://www.pandasppn.org/treatment/

*Link to NIMH PANDAS Questions and Answers https://www.nimh.nih.gov/health/publications/pandas/index.shtml

Link to NIH Genetic and Rare Diseases Information Center https://rarediseases.info.nih.gov/diseases/7312/pandas

Given that we can provide enough credible scientific evidence to show that a full range of treatment options for PANDAS/PANS should be adopted as medical policy with respect to covered services; and that we can provide information from peer reviewed studies supporting the full range of treatment options as well as links to guidelines from national Physician Specialty Societies; that we can provide a list of prudent physicians practicing in relevant clinical areas; as well as the provision of other clinically relevant factors, we believe that the Standard of Care is clearly available and should be adopted by insurers immediately. The criteria for best practice treatment guidelines, as defined by insurer policies as well as by the mandatory changes to business practice determined by legal precedent, have been met.

The insurers' Physicians Advisory Committees and Medical Policy Review Boards need to fill the obvious hole in the range of treatment coverage for PANDAS/PANS. Making the full range of treatment available now may be a short term investment for a bigger long term gain. It clearly makes no fiscal sense for health insurance policies to ignore the children who are at risk for suffering both long term physical and mental consequences and who may become be a continued drain on the health insurance system. If we have the full range of treatments available and covered for these children, we can stop that from happening. Not every child who presents with PANDAS/PANS requires immunomodulatory treatment if it is caught early. But we are finding that physicians cannot exercise their best and full clinical judgement in order to provide medically necessary care to the children who meet the criteria for diagnosis of PANDAS/PANS (see

http://online.liebertpub.com/doi/abs/10.1089/cap.2014.0084 Clinical Evaluation of Youth with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS): Recommendations from the

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2013 PANS Consensus Conference). At this time our hands are tied when it comes to providing sufficient care for patients with PANDAS/PANS and children are suffering.

We are requesting that insurance providers adopt the standard of care that is available on the PANDAS Physicians Network website and is supported by the National Institute of Mental Health, the PANDAS/PANS Collaborative Consortium, and the Illinois PANDAS/PANS Advisory Council with expediency. A full range of treatment options needs to be available for doctors to prescribe to children who meet the PANDAS/PANS diagnostic criteria.

Sincerely,

Yujuan Zhang

3/6/2017

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